

I Am Number 17
June's experience

I am a result of a post term delivery caught unduly unprotected by the amniotic fluids of my mother because she had me at the 11th month, with a fontanelle that retained ground rice which she was eating when she went into labour. It was as if I refused to be born because I knew what would assail me. I was the infant who brought tears to my parents' faces when the midwives and nurses broke the news "June has been diagnosed with sickle cell anaemia; I am sorry".

I became the result of sleepless nights, countless trips to hospital, missed school days, midnight ambulance call outs, an expensive cost to the health care system, a social inconvenience stemming from the unpredictability of my disease, banned from playing PE in school, riding a bicycle or even swimming as all activities with the smallest exertion meant more nights in hospital.

I am eyes gone yellow because my liver does not process waste fast enough to leave my body, so I get jaundiced, I am flawed faulty genes, hips damaged from avascular necrosis, constant x-rays, lumbar punctures, heart scans, and red cells insufficient. I am hospital wards, clinic corridors, waiting rooms, scan rooms, MRI scans and claustrophobia, hospital beds and complex treatments. I am doctors' subject of discussions, the high risk one, and the one "we need to keep an eye on". I am on daily medications, litres of water, hip replacements, acute chest syndrome, sickle retinopathy, bone infarctions, lung damage and mood swings.

But I allow myself to be helped, loved and saved. My loved ones are an essential part of me getting through this disease and in having a stable mental health. I get support from counselling, journaling, art, writing and travelling. Sometimes I get misjudged by this hidden disability, the need to prove I am in pain because I look fine and I have a little make up on that accentuates my cheekbones, or to prove that I am suffering internally or just the need to receive compassion and empathy from colleagues and sometimes friends, the need to make people understand that pain cannot be seen, pain is a feeling that can only be felt by the subject suffering and therefore I continue to battle the concept and break barriers surrounding the fact that people can only have empathy based on what they can see and if pain cannot be seen, how do we empathise with others who go through it. Well, here is a case staring in front of you.

I asked my loved ones what they see in me when they see sickle cell.

"What I see in her is a fighter. She is here, she is with us. She does more than anyone I know. And that's a true sense of overcoming, getting on with it. Those people you see with awful conditions, they get on with it. People have the cold, or flu and they moan about it. Then you look at the people who have real issues. But that's what I see in her; a warrior. And out of her pain shines a light as I see her helping others. Being that beacon of change. Coaching others going through these things, to help them overcome. Helping out in the charities. Sharing her story so other people don't suffer."

Sickle cell has not been the biggest challenge I have lived through in life. It's been one of many life challenges but certainly the most repressive. People get to deal with life challenges every day but to top it with a chronic disease that brings a lot of pain and suffering is another ball game, I have had to deal with a lot of pain all my life. A disease that presents itself with excruciating pain that feels like people are using hammers to hit you with an aim to break your bones cannot be very easy to live with all your life. Its affected nearly every aspect of my life. Fortunately, it hasn't completely defined my life and my identity. As a child, what I knew was what I knew, and I didn't necessarily draw equivalences with other people's lives to see if my experience was the same as theirs. I just went with the flow. But I became an adult and I realised that this is something I had to accept; to endure ongoing and long periods of pain and suffering. Sickle cell is like a refining challenge, like a fire, which you put a precious metal into and after you have left the metal in there and poured it out, it's better off. It's given me a set of experiences which I apply to my everyday life and which contextualises my being. Being able to deal with pain helped me show compassion to the world and to myself. It's given me a very different kind of strength and resilience that I never thought I could have. And in all the pain and suffering, I consistently find meaning in it and its paved some beautiful experiences I never would have thought I would have in my lifetime.

Your red blood cells are round and mine are shaped like sickles. My name is June and I was diagnosed with sickle cell, a genetic blood disorder that affects the red blood cells.

I am one of 17.

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